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Evaluating the Extent of Patient-Centred Care in a Selection of ESC Guidelines

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INTRODUCTION

One of the fundamental efforts to improve healthcare for patients with cardiovascular conditions has been the development of clinical practice guidelines. The ultimate goal of such guidelines is not only to guide healthcare practitioners in providing care, but also to support patients in evidence-based decision-making about appropriate, safe, and efficient care [1, 2]. Rigorous, trustworthy guidelines should provide an integration of scientific evidence, clinicians' expertise as well as patients' values and preferences [2]. Although previous research demonstrated that patient involvement during guideline development is of great value [3-7], evidence-based treatment and patient-centred care are often viewed incorrectly as opposing ideas. Numerous patient associations, scientific societies and professional bodies involved in guideline development, such as the Institute of Medicine (IOM), explicitly consider patient and public involvement to be a key component of guideline development [2, 8-11].

Hence, clinical practice guidelines should nowadays place the patient at the centre of care whilst taking the current level of evidence into account [12]. Based on the definition developed by the IOM Committee on Quality of Health Care, patient-centred care is defined as “*care provided to patients as respectful of, and responsive to, individual patient preferences, needs and values, ensuring that patient values guide all clinical decisions*” [13]. According to the Royal College of General Practitioners, patient-centred care comprises three elements: (i) a holistic approach to patient care, (ii) flexible care which tailors support according to an individual's personal priorities, needs and individually defined outcomes, and (iii) collaborative work between patients and all professionals involved in caring for them [14].

Furthermore, a call is made to use the term ‘person-centred’ instead of ‘patient-centred’ care, highlighting the focus in care towards the person behind the patient and the respective diagnosis [15]. However, there appears to be important differences in the way patient- or person-centred care is understood by healthcare providers, educationalists, professional leaders, and patient organizations originating from their respective backgrounds and roles [16].

Studies demonstrated that involving patients in guideline development facilitates guideline uptake and implementation [3, 8, 17]. Furthermore, the development and use of patient-centred guidelines was found to result in improved quality of care, increased patient satisfaction, efficiency, better treatment adherence, improved disease-related knowledge, healthcare behaviours, patient empowerment; while decreasing complication rates related to long-term conditions, healthcare costs and utilisation [2, 4-7, 14, 18].

One of the cornerstones to ensuring that patients remain at the centre of care is the involvement of patients and patient organisations in the development, implementation, and endorsement of clinical practice guidelines [2, 18]. Patient involvement or engagement can be defined as “*a set of behaviours by which patients can take responsibility for different aspects of their health and illness, while healthcare professionals take cognisance of patient preferences, choices and needs when planning care*” [19]. It signals a paradigm shift from a paternalistic medical dominance to one that embraces partnership with patients and families in planning care. Moreover, it combines patients’ knowledge, skills, ability and willingness to manage their own health care with interventions designed to increase activation and promote positive patient behaviours.

Despite the widespread acceptance of the importance of engaging patients in the development of clinical practice guidelines, it remains unknown to what extent clinical practice guidelines actually incorporate patients' views, preferences, needs and values. The European Society of Cardiology (ESC) recently considered 'Patient Engagement' as a strategically powerful tool to achieve the ESC's mission of reducing the burden of cardiovascular disease [20]. In order to incorporate the principles of patient- or person-centred care within the ESC activities, a systematic analysis of the representation of the principles of patient-centred care in ESC clinical practice guidelines was deemed appropriate. Therefore, the aim of this study was to evaluate the incorporation of patient-centred care within a selection of guidelines published by the ESC between 2015 and 2017.

METHODS

Developing a Checklist Criteria to Determine the Extent of Patient-Centred Care within Clinical Practice Guidelines

Our literature review did not reveal any published comprehensive checklist criteria or consensus on a standard set of criteria for assessing the level of incorporation of patient-centred care in clinical practice guidelines. Therefore, based on the definition of patient-centred care, as formulated by the IOM [2, 13] and in line with the key criteria defined by the Royal College of General Practitioners [14], a checklist of criteria enabling the assessment of the incorporation of patient-centred care in clinical practice guidelines was developed by the

Science Committee Members of the Association of Cardiovascular Nurses and Allied Professionals (ACNAP) which is part of the ESC. The formulated set of criteria was further refined in accordance with a narrative review of publications on patient centeredness and documents containing criteria for patient-centred development of guidelines such as the National Institute for Health and Care Excellence (NICE) in the UK [6, 9, 10, 11, 16, 21, 22, 32, 33]. In addition to the available body of literature, the diverse multi-disciplinary expertise of our committee members, some of whom served on various guidelines development committees in various European countries and others who have special interest in patient-centred care, enabled us to produce a practical checklist to enable the assessment of the patient-centeredness of clinical guidelines. The initial list of criteria was revised by the members of the Science Committee in order to verify the clarity of the items. The checklist was also pilot tested on some of the guidelines by committee members and the findings were discussed in the group. This pilot testing phase was important to discuss the interpretation of the items as well as the principles used to evaluate the items, respectively. The newly developed checklist shown in *Table 1* comprised a list of five categories and included a total of 18 items. The five respective categories were: (i) Patient voice and involvement; (ii) Multidisciplinary involvement; (iii) Holistic care is recommended; (iv) Care is flexible to meet needs; (v) Inclusion of patient tools.

Selection of ESC Guidelines for Review

At the commencement of this project, nine most recent ESC guidelines, published between 2015 and 2017, covering cardiovascular conditions were selected for the purpose of this study (*Table 2*) [23-31]. Guidelines were selected based on the clinical expertise of the committee members and a restriction to the 2-year period was chosen based on pragmatic reasons. While selecting the guidelines, we endeavoured to ensure a broad representation on a range of guidelines and the comprehensive management of patients with a variety of cardiovascular conditions.

Assessing the Guidelines

The first step aimed to ensure uniformity and consistency in the evaluation process and the interpretation of the 18-item checklist. Therefore, all committee members were asked to evaluate the same guideline using the checklist criteria. Members of the committee then met and discussed their results and findings. The meaning and interpretation of each item and evaluation criteria were discussed in order to guarantee uniformity in the evaluation and scoring and followed by the formal assessment of the selected ESC guidelines. Sets of two members of the Science Committee, using the list of evaluation criteria, independently assessed these guidelines. Results from these independent assessments were compared and in case of disagreement, the respective members discussed their ratings and established consensus. All 18 items were evaluated using a standardised evaluation form, using a nominal scale. Reviewers were asked to rate if the item was present, absent, unknown or not clearly described,

or not applicable. Initial answers were converted to a dichotomous scale, indicating whether criteria were met (Yes (Y)) or not (No (N)). The unknown or not clearly described category was classed as a (No (N)). The positive responses (i.e., Yes) on all items within each of the respective five main categories were summed and converted into percentages reflecting the cumulative achievement of all ESC guidelines to specified criteria under each category. Supporting comments or notes provided by the reviewers to justify their assessments were subsequently subjected to thematic analysis to identify key themes and patterns.

RESULTS

For all nine selected ESC guidelines [23-31], the level of achievement of patient-centred care criteria is presented in *Table 3*. Multidisciplinary involvement from various healthcare professionals during the composition of the guidelines was ranked the highest for achievement with 53% across the assessed ESC guidelines. Conversely, advocating appropriate patient tools for use as decision aids had the lowest achievement rate of 4%, closely followed by involvement of the patient/representatives in guideline writing and inclusion of the voice of patients through their experiences at 9%. Charts and tables, which further highlight the results to depict the rate of achievement for each individual guideline, are located within the Supplementary Materials (Figures S1-S5; Tables S1-S5).

Patient voice and involvement

No information was retrieved from any of the respective guidelines about inclusion of patients or representatives in the development of the respective guidelines. Hence, no information demonstrated that patients or representatives were members of the guideline writing committee. Whilst some guidelines acknowledged several studies investigating patient experiences (i.e., ‘Diagnosis and treatment of acute and chronic heart failure, 2016’ [29] and ‘Diagnosis and management of pericardial diseases, 2015’ [23]), the depth of coverage and emphasis placed on enhancing patient empowerment and improving patient-centred care was sparse.

Four guidelines (‘Management of dyslipidaemia, 2016’ [26]; ‘Management of atrial fibrillation, 2016’ [27]; ‘Diagnosis and treatment of acute and chronic heart failure, 2016’ [29]; and ‘Diagnosis and management of pericardial diseases, 2015’ [23]) referred to patient-related outcomes, referenced from studies investigating patients’ experiences. Most of these studies focussed upon improving treatment adherence and addressing patient barriers. Two other guidelines (i.e., ‘Management of Acute Myocardial Infarction in patients presenting with ST-segmentation, 2017’ [31]; ‘Cardiovascular Disease Prevention in Clinical Practice, 2016’ [28]) recognised and referred to the need for good professional-patient relationships to make patient-orientated decisions but did not explicitly include studies of patients’ experiences with relevant medical treatment.

Multidisciplinary involvement

The guidelines' writing committees stated that the ESC has selected experts to contribute to the writing and development of guidelines and a broad range of international cardiology societies, councils and working groups were involved in the development of the guidelines. However, by reviewing the list of committees and ESC national societies actively involved in writing the guidelines, it was not possible to determine if these societies and parties represented cardiologists, cardiovascular nurses, pharmacists, allied healthcare professionals and other related disciplines. Thus making it difficult to determine the true extent of multidisciplinary representation within the guideline-writing committees.

Guidelines often referred to allied healthcare professionals (i.e., multidisciplinary specialists) who contribute to patient care. However, different disciplines may only be listed without elaboration on the specific input or roles that they have in relation to patient care. For example, in the guideline for the management of infective endocarditis [25], the authors stated the need for a multidisciplinary endocarditis team that includes a microbiologist, cardiologist, imaging specialist, cardiac surgeon and specialist in coronary heart disease. In addition, the Cardiovascular Disease Prevention in Clinical Practice 2016 guideline [28] reports on the importance of nurse-led interventions, and also names physicians, dieticians, psychologists and experts in rehabilitation and sports medicine, although no mention of pharmacists or physiotherapists was reported. The guideline on "Diagnosis and treatment of acute and chronic heart failure, 2016" [29] also mentions the importance of close collaboration between

cardiologists, specialist nurses, general practitioners and other experts, including pharmacists, dieticians, physiotherapists, psychologists, palliative care providers and social workers.

Holistic care is recommended

There was a variability in holistic coverage of patients' needs. The guidelines on "Management of dyslipidaemia, 2016" [26], and "Management of Acute Myocardial Infarction in patients presenting with ST-segmentation, 2017" [31] covered most aspects of providing care tailored to individual patient needs. The dyslipidaemia guideline [26] had an entire section dedicated to patient education and emphasis was placed on developing an empathetic informal/formal caregiver-patient relationship to provide holistic care. In addition, the "Diagnosis and treatment of acute and chronic heart failure, 2016" guideline emphasised the importance of patient education and support as well as the significance of self-care [29]. Other guidelines have mentioned the provision of patient advice with regards to adjusting lifestyle factors, such as smoking cessation and weight loss, although coverage of the total holistic management of patient needs was not deemed comprehensive.

Care is flexible to meet needs

Seeking patient opinion and including patients as a part of shared decision-making was recommended in some of the guidelines. Four guidelines, the "Management of dyslipidaemia, 2016" [26], "Management of atrial fibrillation, 2016" [27], and "Cardiovascular Disease Prevention in Clinical Practice, 2016" [28] had specific sections that focused on encouraging

treatment adherence, improving lifestyle factors or other patient-related considerations. To improve treatment adherence and patient outcomes, it was acknowledged that a communicative and empathetic relationship between the healthcare professional and patient was required to make patient-centred decisions with regards to treatment and care.

Although it is acknowledged that patient education is important, and advice given should be applied to the specific context of the patient's lifestyle, preferences, habits, priorities and goals; no specific recommendations or guidance on how to tailor information to individual needs were identified in the selected list of guidelines.

Inclusion of patient tools

Whilst all ESC guidelines provide summary versions of their guidelines, these are composed with medical terminology and aimed towards healthcare professionals. None exist which are specifically adapted for the understanding of patients. Patient tools usually incorporate messages that are more comprehensible and therefore are supposed to increase their acceptability by patients. One guideline ("Management of atrial fibrillation, 2016" [27]) referred the use of patient decision aids to support shared decision-making; however, no tools were specifically suggested. While the heart failure guideline ('Diagnosis and treatment of acute and chronic heart failure, 2016' [29]) recommends visiting the website <http://www.heartfailurematters.org> "...for those patients and families with Internet access", it does not specify what the website contains and why it should be visited.

The key themes identified in the supporting comments provided by all reviewers to justify the evaluation selection for each category of the patient-centred care criteria for all nine ESC guidelines is presented in *Table S6* in the supplementary material.

DISCUSSION

In this study, we assessed the nine ESC guidelines, published between 2015 and 2017, on the extent to which they incorporate elements of patient-centred care into their respective recommendations based on a comprehensive list of evidence- and expert-based criteria developed for the purpose of this study. This is the first study reviewing European guidelines in cardiovascular care addressing the level of patient-centeredness. The ESC is a non-profit organisation with a leading role in the development and dissemination of evidence-based guidelines for the prevention, diagnosis, treatment and management of cardiovascular conditions. As stated in their mission, ESC aims to develop clinical practice guidelines on a wide range of cardiovascular conditions with the aim to help clinicians balance out the risks and benefits of specific therapeutic options or management strategies. Hence, the respective guidelines are still considered primarily as educational tools that support clinicians to make diagnostic, clinical and therapeutic judgements. Although consensus is growing that patient-centred guidelines are required in order to enable to increase participation in care and prepare patients to make well-informed decisions about their care, patients appeared unfortunately not

explicitly considered part of the target population of ESC guidelines. In order to facilitate the process of guideline development, ESC issued a specific 'Recommendation for Guidelines Production' document [32]. This manual aims to formalise the developmental process including all steps when selecting, writing, updating, maintaining and endorsing clinical practice guidelines. Although ESC states that task forces and guideline committees should include a balanced representation of clinical cardiologists, allied health professions, epidemiologists, and pharmacologists as the composite panel of stakeholders, the incorporation of patients, families, or patient representatives is not put forward. Finally, in reviewing the ESC recommendations on guideline development, no endorsement through patient organisations was mentioned, nor was there a request to explicitly incorporate patient-friendly decision or education tools in the guideline, nor to involve patients or patient organisations in writing, updating, reviewing or disseminating the respective recommendations.

Overall, this current review of selected ESC guidelines revealed that although the guidelines encourage good patient-professional relationships, no patient representative was found in task forces for guideline development. Only four out of nine guidelines had specific sections to address treatment adherence and other patient-related issues but overall there was a minimal number of studies on patient experiences included.

Some methodological limitation need to be acknowledged when interpreting the results of this study. Performing this review was challenging since standardised methods and measures are lacking for this type of research and we therefore developed a new innovative approach. As there is currently no consensus on the criteria used to evaluate the level of patient-centredness

of guidelines, a list of relevant evidence- and eminence-based criteria was developed for the purpose of this study. Although this list was composed based on a narrative literature review and expert consensus within the Science Committee, this list was not validated nor tested in other studies. Furthermore, although guidelines were assessed by at least two sets of committee members independently and consensus was reached through multiple discussion meetings, we did not calculate the level of inter-rater agreement or reviewer consistency. However, both similarities and differences in items evaluations were discussed between raters and final consensus was reached by the reviewers on the selected set of guidelines being assessed.

Despite these limitations, it is important to emphasise that this review is unique in that it is, to our knowledge, the first time that review criteria around patient-centred care has been developed and applied to a selection of ESC guidelines. We were able to demonstrate that there is room for addressing various elements of patient-centred care in the five areas examined, as defined in our stud. While we only reviewed nine ESC guidelines, which can be seen as a limited set of guidelines, we believe they reflected a broad range of up to date guidelines on the comprehensive management of patients with a variety of cardiovascular conditions. Furthermore, we made a selection of guidelines to keep the project manageable in terms of demands of time and resources.

In order to have a greater impact on clinical practice and increase the likelihood that guidelines are accepted and implemented by all stakeholders, including both practitioners and patients, the role of patient preferences and personal choices should be taken into account [2]. Some scientific and professional associations or societies provide the writing committees with clear

instructions on how to involve the patients' perspective in guideline development [9-11]. Committees in charge of developing and writing guidelines are preferably multidisciplinary with a balanced representation of practitioners (e.g., generalists, specialists, academics, allied professions, nurses, pharmacists and pharmacologists) and other individuals who have experienced the condition, treatment or the healthcare program in question (e.g., patients, families, community members, patient organisations) [9-11, 21].

Finally, healthcare providers often state that there is an immense gap between evidence-based clinical practice guidelines aiming at advising clinicians on the best treatment options available, and the provision of patient-centred care. Providing patient-centred care is a holistic process that requires healthcare providers to interact with patients on a one-to-one basis to design a care plan in line with the individual needs, expectations and preferences of each patient. The development of person-centred clinical practice guidelines, however, could fill this void as it is considered as a tool ensuring that clinicians receive instructions helping them incorporate patients' preferences into the care plan. Furthermore, actively involving patients in the establishment of guidelines increases the likelihood that patient information aids, decision-making tools, or other patient resources are incorporated in the evidence-based care plan, both in acute and chronic cardiovascular management.

Recommendations

We recommend that definitions, criteria, categories or principles of patient-centred care are included when developing and endorsing new clinical guidelines. This can be supported by

ensuring that guidelines meet as many as possible of the new set of criteria that we developed in this study based on various definitions, publications, and expert opinion on what constitutes patient-centred care and what makes guidelines patient-centric [1,2,6,8,9,10, 11, 13, 14, 16, 21, 22,32, 33]. The newly developed checklist criteria can also be used to assess the levels of patient-centred care in clinical guidelines in general and not only those which cover cardiovascular disease. The five categories that clinical guidelines should take into account to be more patient-centric are: (i) Patient voice and involvement; (ii) Multidisciplinary involvement; (iii) Holistic care is recommended; (iv) Care is flexible to meet needs; (v) Inclusion of patient tools, as detailed in *Table 1*. To guarantee that healthcare professionals provide patients the greatest benefit, respect for patients' preferences, in particular, should be safeguarded. Concrete actions are likely to increase the quality of information needed by healthcare professionals when treating patients with cardiovascular conditions. The involvement of patients and patient organisations should be clearly demonstrated within the writing group from the developmental stage onwards. Patient organisations can also play a vital role in the evaluation and follow up of implementation of guidelines as well as in lobbying and policymaking for ensuring equal and evidence-based care. To ensure a truly multidisciplinary approach in guideline development, the specialities and roles of all healthcare professionals acting as members of the guidelines' writing committees should be documented in detail.

Despite the acknowledged importance of patient-centred care, a considerable amount of work remains to ensure that clinical guidelines do include a representation of patients and patient

organisations in the guideline developmental process. Furthermore, the inclusion of a multidisciplinary healthcare professional team is also key to delivering optimal patient care for people with long-term cardiovascular conditions. Writing committees should, however, be provided with the mandatory support, guidance and tools enabling them to increase the incorporation of patient-centred care elements in guideline development.

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Not applicable

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Table 1: Incorporation of patient-centred care criteria in ESC guidelines.

Main category	Number of criteria to meet	PCC incorporation across selected ESC guidelines (Yes %)
Patient voice and involvement	5	9
Multidisciplinary involvement	4	53
Holistic care	7	38
Flexible to meet needs	4	31
Patient tools	3	4

Percentage of achievement for the nine selected ESC guidelines in meeting the category criteria, as defined in Table 1S, for patient-centred care.

PCC = patient-centred care

Table 2: Key themes identified in thematic analysis.

Main category	Key themes identified
Patient voice and involvement	<ul style="list-style-type: none"> • No patient representative in guideline development • Encourages good patient-professional relationships • 4 guidelines had specific sections to address treatment adherence and other patient-related issues • Minimal studies of patient experiences included
Multidisciplinary involvement	<ul style="list-style-type: none"> • Breadth and diversity of multidisciplinary involvement in guideline writing appears minimal • CCNAP is most diverse multidisciplinary council to participate in guideline development but unclear if involved with the writing committee
Holistic care	<ul style="list-style-type: none"> • Variability in holistic coverage of patient needs • Co-morbidities often raised as an issue for patients but the context is medically-focussed • Acknowledges importance of multidisciplinary involvement, however no description of input or contribution listed • Non-medical professionals not referred to as a ‘multidisciplinary team’
Flexible to meet needs	<ul style="list-style-type: none"> • Recommends seeking patient opinion and to include patients as part of shared decision-making • Encourages patient education but most do not specify tailoring education to individual needs

Patient tools	<ul style="list-style-type: none"> • No ‘patient-friendly’ guideline versions available • Acknowledged in one guideline that patient decision aids should be considered but none were provided • Condensed versions (pocket guidelines), summary cards and slide-sets available but for healthcare professional use
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Summary of key themes identified through thematic analysis of reviewers’ comments during evaluation of ESC guidelines.

CCNAP = Council on Cardiovascular Nursing and Allied Professions

Supplementary Table S1

Criteria to determine the extent of patient-centred care within the recommendations of ESC guidelines.

Category	Patient-centred criteria
Patient voice & involvement	<p>Presence of a patient representative in the guidelines writing committee.</p> <p>Consultation with patient bodies as stake holders and contributors to guidelines.</p> <p>Patients or patient bodies can register as stake holders.</p> <p>Consulting or representation with patient(s) with the condition covered in the guidelines, or a representative of a body of patients affected by the condition.</p> <p>Inclusion of studies on patients’ adherence with or experience with relevant medical treatment in the guideline’s evidence base.</p>
Multidisciplinary involvement	<p>There is multidisciplinary representation on the guidelines writing committee. This includes generalists, specialists, academics and healthcare professionals from various disciplines e.g. nurses, pharmacists, physiotherapists etc.</p> <p>There is the option for professional healthcare bodies or organisations (NMC, RPhS etc.) to register as a stakeholder</p>

	<p>Contribution is sought from various national and international healthcare professional bodies.</p> <p>Representatives from various members of the healthcare team.</p>
Holistic care is recommended	<p>The guideline considers all patient needs including:</p> <ul style="list-style-type: none"> (a) Transition of care needs (b) Multiple co-morbidity needs (c) Communication needs (d) Communicating with healthcare professionals looking after the patient (e) Communicating with carers and families (f) Psychological needs <p>Input and role of multidisciplinary team members in patient care is acknowledged or highlighted.</p>
Flexible to meet needs	<p>Patient opinion is sought</p> <p>Clear recommendations to assess patient preference and beliefs and respect choices.</p> <p>Recommendations to provide patient education tailored to patient needs.</p> <p>Recommendation to provide patient with a care record or inform them of care plan at different parts of the healthcare continuum.</p>
Patient tools	<p>Decision aids provided</p> <p>Recommendation to use decision aids</p> <p>A patient friendly version of the guideline is available.</p>

Supplementary Table S2

List of ESC guidelines evaluated for patient-centred care.

Key*	ESC guidelines evaluated
1.	Valvular heart disease (Management of). 2017
2.	Acute myocardial infarction in patients presenting with ST-segment elevation (Management of). 2017
3.	Dyslipidaemias (Management of). 2016
4.	Acute and chronic heart failure (Diagnosis and treatment of). 2016
5.	Atrial fibrillation developed in collaboration with EACTS (Management of). 2016
6.	Cardiovascular disease prevention in clinical practice. 2016
7.	Infective endocarditis (Guidelines on prevention, diagnosis and treatment of). 2015
8.	Pericardial diseases (Diagnosis and management of). 2015
9.	Pulmonary hypertension (Diagnosis and treatment of). 2015

EACTS, European Association for Cardio-Thoracic Surgery; ESC, European Society of Cardiology

*Key corresponds to guideline numbering system in Tables S3-S7.

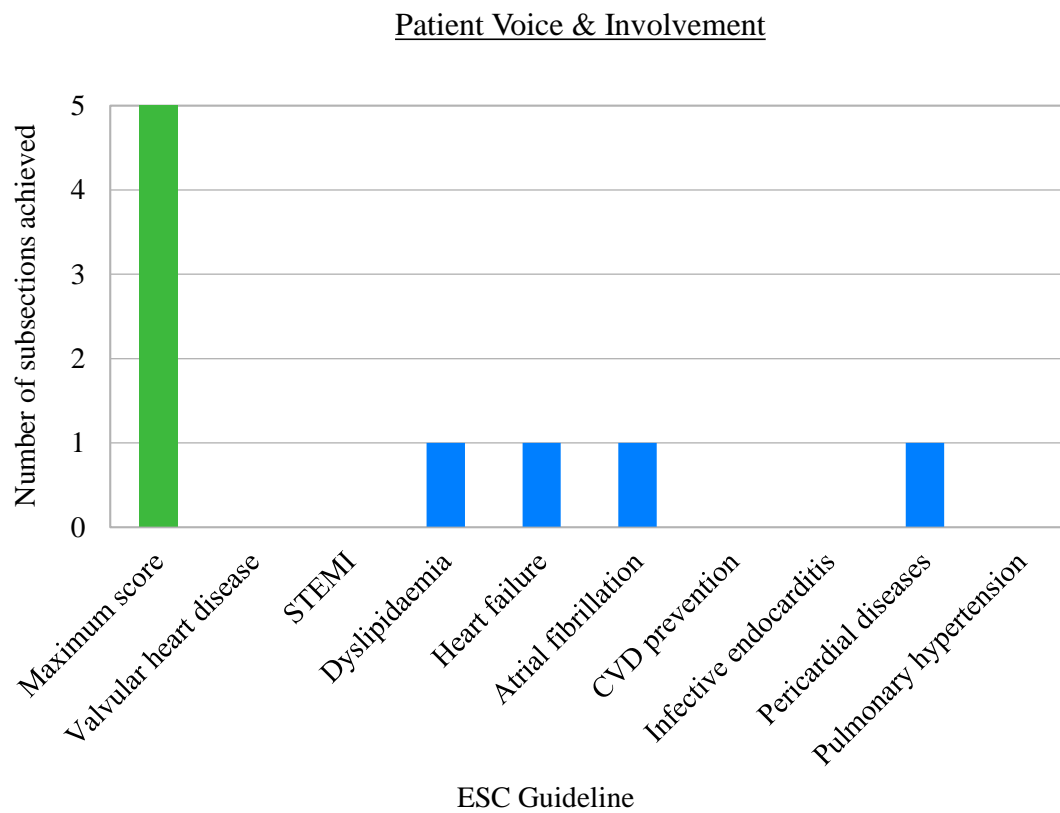
Supplementary Table S3

Achievement of criteria within the 'patient voice & involvement' category.

	Guideline number*								
Patient voice & involvement	1	2	3	4	5	6	7	8	9
1. Presence of a patient representative in the guidelines writing committee	N	N	N	N	N	N	N	N	N
2. Consultation with patient bodies as stake holders and contributors to guidelines	N	N	N	N	N	N	N	N	N
3. Patients able to register as stake holders	N	N	N	N	N	N	N	N	N
4. Evidence of consulting with representation of patients with the condition covered	N	N	N	N	N	N	N	N	N
5. Inclusion of studies on patients' experience with proposed intervention(s)	N	N	Y	Y	Y	N	N	Y	N

* Numbering key corresponds to Table S2. N = No, item not applicable; Y = Yes, item applicable

Supplementary Figure 1S



Whether patients' experiences and voices are acknowledged and represented within ESC guidelines.

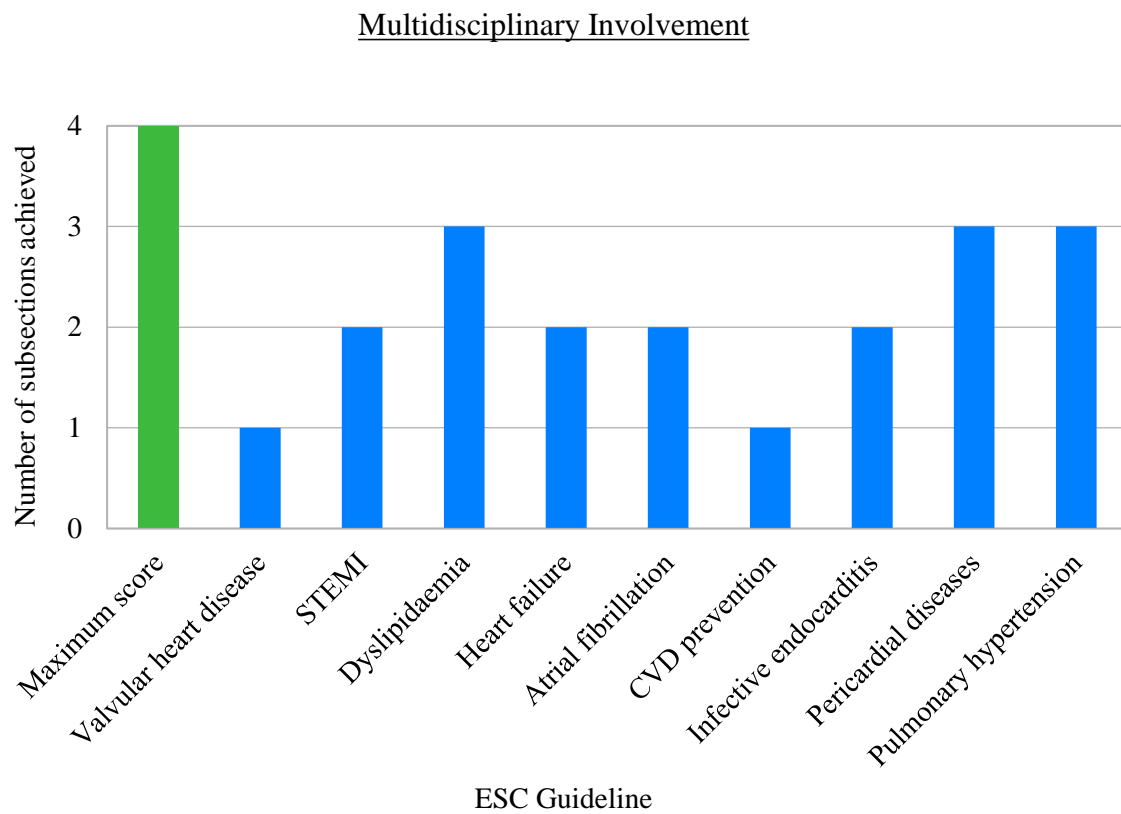
Supplementary Table S4

Achievement of criteria within the 'multidisciplinary involvement' category

	Guideline number*								
Multidisciplinary involvement	1	2	3	4	5	6	7	8	9
1. Multidisciplinary representation on the writing committee	N	N	Y	Y	Y	N	Y	Y	Y
2. Professional healthcare bodies can register as stake holders	N	N	N	N	N	N	U	N	U
3. Multi-professional diversity in healthcare bodies registered as stake holders	N	Y	Y	N	N	N	U	Y	Y
4. Contribution from national and international healthcare professional bodies	Y	Y	Y	Y	Y	Y	Y	Y	Y

* Numbering key corresponds to Table S2. N = No, item not applicable; Y = Yes, item applicable; U = unclear whether item applicable

Supplementary Figure 2S



Degree of involvement from multidisciplinary professionals in composing ESC guidelines.

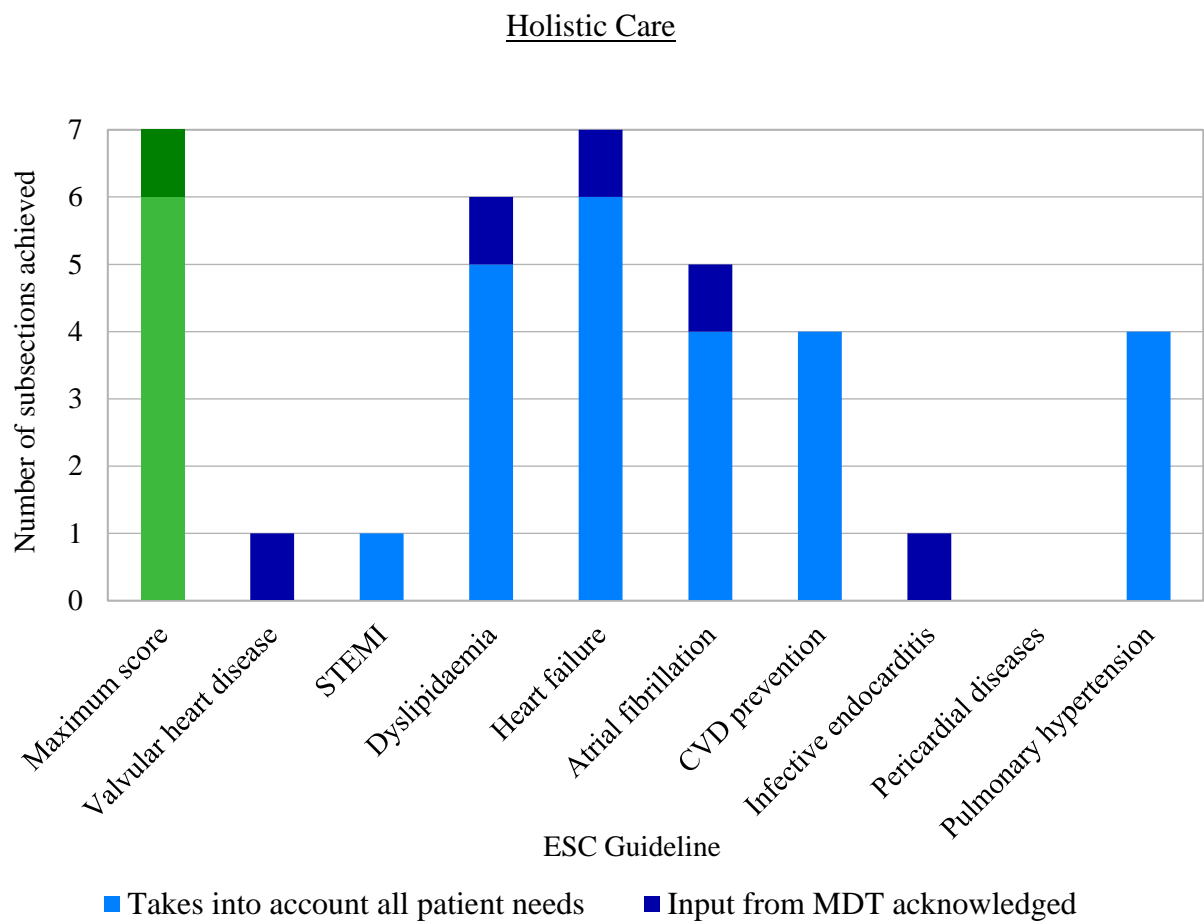
Supplementary Table S5

Achievement of criteria within the 'holistic care is recommended' category.

	Guideline number								
Holistic care is recommended	1	2	3	4	5	6	7	8	9
1. Guidelines consider all patient needs:									
<i>(a) Transition of care</i>	N	Y	N	Y	Y	Y	N	N	Y
<i>(b) Multiple co-morbidities</i>	N	N	Y	Y	Y	N	N	N	Y
<i>(c) Communication needs</i>	N	N	Y	Y	Y	Y	N	N	Y
<i>(d) Communicating with other healthcare professionals involved in care</i>	N	N	Y	Y	Y	N	N	N	N
<i>(e) Communicating with carers and families</i>	N	N	Y	Y	N	Y	N	N	N
<i>(f) Psychological needs</i>	N	N	Y	Y	N	Y	N	N	Y
2. Input and role of multidisciplinary team members acknowledged	Y	N	Y	Y	Y	N	Y	N	U

* Numbering key corresponds to Table S2. N = No, item not applicable; Y = Yes, item applicable; U = unclear whether item applicable

Supplementary Figure 3S



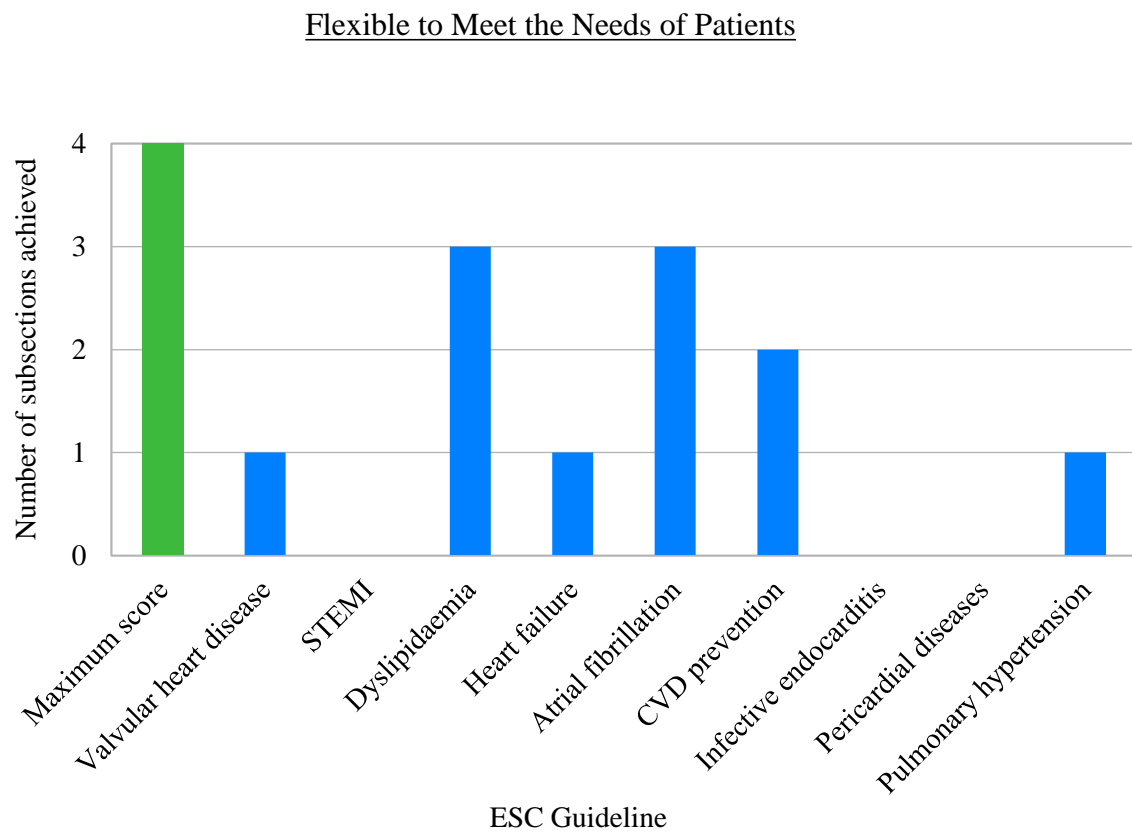
Supplementary Table S6

Achievement of criteria within the 'flexible to meet needs' category.

	Guideline number								
Flexible to meet needs	1	2	3	4	5	6	7	8	9
1. Evidence that patient opinion is sought	N	N	Y	N	Y	Y	N	N	N
2. Clear recommendations to assess patient preference and beliefs and respect choices	Y	N	Y	Y	Y	Y	N	N	Y
3. Clear recommendations to provide patient education tailored to patient needs	N	N	Y	N	Y	N	N	N	N
4. Recommendations to provide patient with a care record or inform them of care plan throughout	N	N	N	N	N	N	N	N	N

* Numbering key corresponds to Table 2-S. N = No, item not applicable; Y = Yes, item applicable

Supplementary Figure 4S



Whether guidelines contain information and recommendations which can be adapted to the patient and accommodate their individual needs.

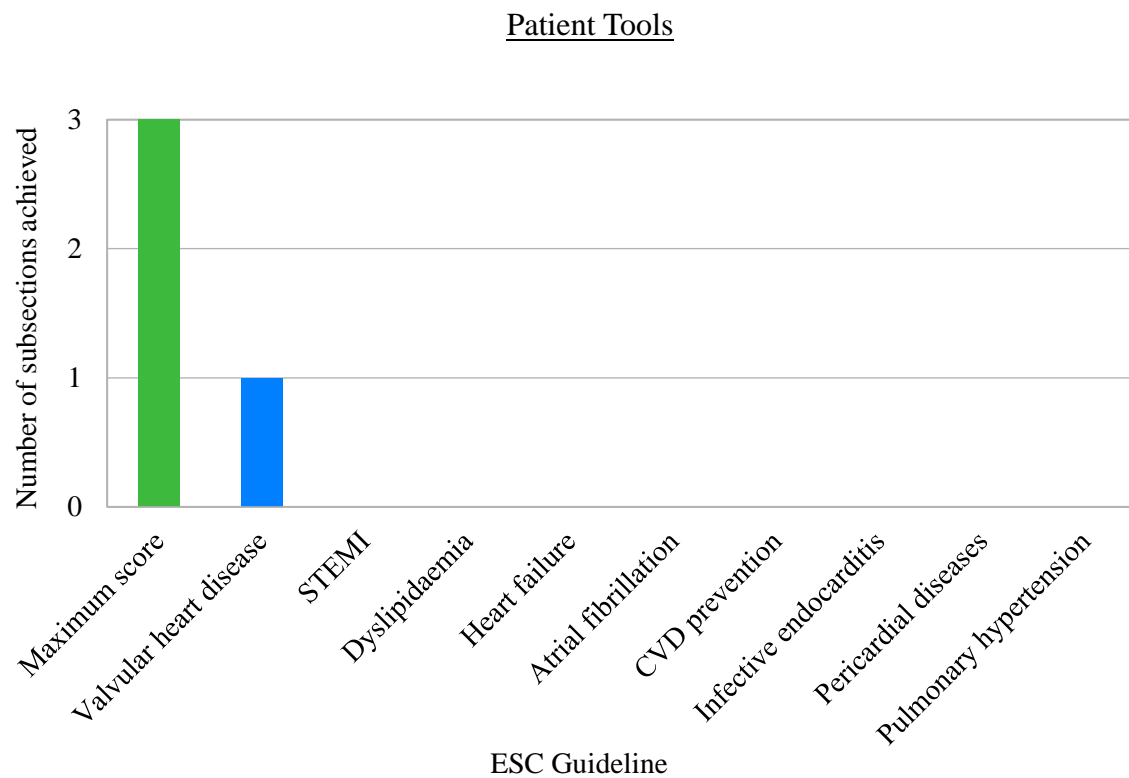
Supplementary Table S7

Achievement of criteria within the 'patient tools' category.

	Guideline number*								
Patient tools	1	2	3	4	5	6	7	8	9
1. Decision aids provided	N	N	N	N	N	N	N	N	N
2. Recommendations to use decisions aids	N	N	N	N	N	N	N	N	N
3. Patient-friendly version of guideline available	Y	N	N	N	N	N	N	N	N

* Numbering key corresponds to Table S2. N = No, item not applicable; Y = Yes, item applicable

Supplementary Figure 5S



Whether guidelines advocate or support the use of tools in assisting patients to make decisions regarding their care and treatment.

Table Legends

Table 1 - The newly developed checklist criteria to determine the extent of patient-centred care within clinical practice guidelines.

Table 2 - List of ESC guidelines evaluated in the study for patient-centred care.

Table 3 - Levels of incorporation of each of the patient-centred care criteria in the nine selected ESC guidelines that were reviewed.

Supplementary Table Legends

Table S1 – Meeting criteria within the ‘patient voice & involvement’ category.

Table S2 – Meeting criteria within the ‘multidisciplinary involvement’ category

Table S3 – Meeting criteria within the ‘holistic care is recommended’ category.

Table S4 – Meeting criteria within the ‘flexible to meet needs’ category.

Table S5 – Meeting criteria within the ‘patient tools’ category.

Table S6 - Key themes identified in the comments provided by all reviewers for each category for all nine ESC guidelines.

Supplementary Figure Legends

Figure S1 – Number of items met in the patients’ experiences and voices category for reviewed ESC guidelines. Patient experience & voice being acknowledged and represented within ESC guidelines.

Figure S2 - Number of items met in the ‘multidisciplinary involvement’ category for reviewed ESC guidelines. The degree of involvement from multidisciplinary professionals in composing ESC guidelines.

Figure S3 - Number of items met in the ‘holistic care is recommended’ category for reviewed ESC guidelines. Level of advocating the need to considering all patients’ needs and acknowledging input from other members of the multidisciplinary team.

Figure S4 - Number of items met in the ‘flexible to meet needs’ category for reviewed ESC guidelines. Level of information and recommendations within the guideline which can be adapted to the patient and accommodate their individual needs.

Figure S5 - Number of items met in the ‘patient tools’ category for reviewed ESC guidelines. The level of guideline advocating and supporting the use of tools in assisting patients to make decisions regarding their care and treatment.